



# MENTAL RETARDATION BULLETIN

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SUBJECT

Family Support Services Subcommittee  
Observations and Recommendations

BY

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## SCOPE:

County Mental Health and Mental Retardation Administrators  
Base Service Unit Directors

Family-Driven/Family Support Services Project Directors

## PURPOSE:

The purpose of this bulletin is to disseminate the general observations and recommendations of the Family Support Services Subcommittee regarding Family-Driven/Family Support Services (FD/FSS) based on the subcommittee's evaluations of the projects.

## BACKGROUND:

The Office of Mental Retardation (OMR) began funding Family-Driven/Family Support Services pilot projects in Fiscal Year 1987-88. During that year, 11 projects were funded. In Fiscal Year 1989-90, 15 additional projects were funded.

Since the Family Support Services Subcommittee of the Office of Mental Retardation (OMR) played a significant role in assisting OMR with designing and implementing the FD/FSS initiative, the subcommittee was charged with responsibility of conducting technical evaluations of each of the pilot projects to determine the extent to which the projects were being operated in accordance with their proposal which was approved by OMR. The subcommittee completed the evaluations of all the projects late in 1992. Detailed reports of each of those evaluations were submitted to the Deputy Secretary for Mental Retardation and to the counties responsible for the projects. Each report identified the strengths and weaknesses of the project.

## REFER COMMENTS AND QUESTIONS TO:

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Based on the formal evaluations of the FD/FSS pilot projects, the subcommittee members initiated a process to identify their general observations of the issues which have surfaced pertaining to the implementation of Family-Driven/Family Support Services in Pennsylvania. It is important to note that, in developing these issues, the subcommittee considered FD/FSS as a whole concept, and did not focus on any specific project. Therefore, the issues identified in this report reflect the general observations of the FSS subcommittee about the status of the Statewide FD/FSS pilot project initiatives.

#### DISCUSSION:

In presenting these observations, the subcommittee has separated them into three categories. The first category represents a sampling of some of the very positive things that have resulted from the initiation of Family-Driven/Family Support Services in Pennsylvania. The second category represents issues which the subcommittee wanted to bring to the attention of the Office of Mental Retardation and counties, but which do not necessarily require specific action other than on-going monitoring by Regional and County staff to avoid potential future problems. Finally, the third category represents issues and actions recommended by the subcommittee that the Office of Mental Retardation and counties should take to address them. The following, therefore, represent the general observations and recommendations of the Family Support Services Subcommittee pertaining to the implementation of Family-Driven/Family Support Services in Pennsylvania.

#### I. A SAMPLING OF THE POSITIVE INFLUENCES OF FAMILY-DRIVEN FAMILY SUPPORT SERVICES

1. As a result of the family-driven approaches, families felt empowered to make their needs known to commissioners, administrators, and legislators in their area. Some of the results of this were:
  - Some county commissioners or administrators advanced money to Family Support Services even though the budget was not yet passed so that services were not denied.
  - Some counties did not stop services to families as a result of a late allocation.
  - Families have been treated with greater dignity as a result of FD/FSS.
  - In one county, project.families felt so empowered that they held a Political Day to meet with their legislators to discuss concerns and issues.
  - Some counties are converting to FD/FSS even if they were not awarded a Pilot Project.

2. Family Driven/Family Support Services have had a greater impact on the system than anyone believed or anticipated.
  - Families have become more active in planning, implementing, monitoring, and evaluating services and activities that affect them.
  - although money wasnot significantly increased, family-driven offered families options that did not exist before.
  - As a result of the design of FD/FSS, program implementors recognize the decision making abilities of families and individuals. This is reflective of an attitude change.
  - The personalized planning inherent in FD/FSS appears to have had a rippling effect in areas outside of family support services. Families want a greater say in all program areas.
  - Families have become more aware of how services are operated and how much they cost. Consequently, many families manage their allocations and stretch their resources more effectively.
  - The flexibility provided through FD/FSS enabled families to receive services they really need.
  - Families pooled resources and more alternatives were developed in some FD/FSS projects.
  - Counties with FD/FSS projects are networking and sharing information among themselves and with other counties which have expressed interest in initiating FD/FSS projects.

## I I . GENERAL OBSERVATIONS

1. Confidentiality is frequently perceived as a barrier to informal supports and service delivery in general.
2. Successful FD/FSS is linked directly to effective case management services.
3. Casemanagers believe in Family Driven/Family Support Services and would like smaller case loads.
4. County Administrators exercise their responsibilities in varying ways in regard to Family Support Services.
5. There are differences from county to county over what constitutes allowable FSS services, and this frustrates some families.

6. It is usually more difficult for a government agency than a provider to get money to a family via cash or a voucher.
7. Families can often negotiate less expensive rates than agencies.
8. Agencies which operate FD/FSS services and are also providers of FSS services have a potential for conflict of interest.
9. FD/FSS is under-resourced:
  - actual money to individual families
  - actual services, both specialized and generic
  - actual money for FD/FSS projects
  - transportation issues: A number of families want to use their FD/FSS funds for transportation, but it remains a restricted service.
10. Conversion from old (either traditional or pilot) to Family-Driven often resulted in a reduction of resources/services to/for specific families because additional families received services with the same resources.
11. The evaluation process used by the subcommittee was an effective method to assess the status of each project and to provide technical assistance and/or feedback regarding the ongoing implementation of the project.

#### I I I . OBSERVATIONS WITH SPECIFIC FSS SUBCOMMITTEE RECOMMENDATIONS

##### Observation #1:

There is confusion about the concept of a community organizer. Many counties use their approved community organizer as a manager (i.e., FSS Coordinator), and not as a developer of informal supports and a person who accesses generic services.

##### Recommendation:

The Office of Mental Retardation should institute a mechanism to provide training/orientation to FD/FSS projects regarding the role of a community organizer. This may involve issuing guidelines to counties/providers regarding community organization, providing workshops on community organization, on-site consultation by the Regional staff or any combination of these types of technical assistance.

Observation #2:

There is confusion regarding the difference between informal supports and generic resources.

Recommendation:

The Office of Mental Retardation should define and clarify the differences between informal supports and generic resources so that projects which include a community organizer can more likely have access to both of those types of resources.

Observation #3:

Casemanagers would benefit from greater information regarding generic services and how to access them.

Recommendation:

The Office of Mental Retardation should encourage counties to promote the development of avenues to identify and access generic services. This may include training/orientation of casemanagers regarding community resources, the development of resource directories and/or redefining the role of casemanagers to involve them in community organization work.

Observation #4:

Family Advisory Councils are functioning in varying capacities.

- Some are very active; others are not.
- Some are widely representative; some are not.
- Some perceive themselves as important and empowered, and others do not.
- Some have a purpose, goals, and roles; others do not.

Recommendation:

The Office of Mental Retardation should promote opportunities for Family Advisory Councils to network and share information. This may involve Regional and/or Statewide conferences, seminars and meetings, inviting councils to attend Regional Mental Retardation Coordinator meetings and/or establishing a formal statewide information network for such councils.

Observation #5:

In a voucher reimbursement model, families may be denied access to services because they have to use their own money to pay for services and then wait to be reimbursed by the project/county.

Recommendation:

Safeguards should be established by counties so that families are not denied access to services because they have to use their own money up front to pay for services.

Observation #6:

Other than determining family satisfaction through surveys and questionnaires, counties tended not to conduct their own evaluations regarding the overall effectiveness of their project.

Recommendation:

At least an annual evaluation should be conducted by the county to determine overall effectiveness of the county's FD/FSS program.

CONCLUSION

Family-Driven/Family Support Services have been successfully initiated in the majority of the FD/FSS pilot projects. Other counties are in the process of developing plans to initiate FD/FSS projects using their existing resources. The Office of Mental Retardation should continue to promote the development and expansion of FD/FSS initiatives through the provision of funding and technical assistance to counties. Likewise, counties should support parents who want to be part of such initiatives. The Family Support Services Subcommittee will continue work with the Office of Mental Retardation and counties to address the issues identified in this report, and to promote the statewide implementation of effective Family-Driven Family Support Services.